Orienting child- and family-centered care toward equity

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Abstract
Child- and family-centered care (CFCC) is being increasingly adopted internationally as a fundamental philosophical approach to the design, delivery, and evaluation of children’s services in diverse primary and acute health care contexts. CFCC has yet to be explored in the context of families and children whose health and health care is likely to be compromised by multifaceted social and structural factors, including racialization, material deprivation, and historically entrenched power imbalances. To date, an equity orientation for CFCC has not been examined or developed. This is a critical area of inquiry, given the increasing evidence that children in families who face such inequities have poor health outcomes. This article examines dominant discourses on CFCC in the context of families and children who are at greater risk of health inequities in wealthy countries, drawing on Canada as a useful example. It outlines an evidence-based approach to equity-oriented care that the authors contend has the potential to orient CFCC toward equity and provide greater clarity in the conceptualization, implementation, measurement, and evaluation of CFCC in ways that can benefit all families and children including those who have typically been excluded from research.

Keywords
Child health, children’s participation, family-centered care, inequalities in health

Introduction
Child- and family-centered care (CFCC) is being increasingly adopted internationally, including in Canada, as a fundamental philosophical approach to the design, delivery, and evaluation of children’s services in diverse primary and acute health care contexts (Coyne et al., 2016; Dennis et al., 2017; Kuo et al., 2012; Power and Franck, 2008), including in the provision of pediatric

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emergency care (Child Health BC, 2016; Dudley et al., 2015; Sick Kids, 2014). Currently there is a lack of consensus on what constitutes CFCC, and how “children” are situated within family-centered care (Al-Motlaq et al., 2018). Common elements of CFCC include health care providers listening to and honoring families and children’s perspectives and choices such that their knowledge, priorities, and beliefs are incorporated into the planning and delivery of care and providing timely and accessible information that affirms and fosters their participation in care and decision-making at a level of their choosing (Byczkowski et al., 2015; Conway et al., 2006; Dennis et al., 2017; Ehrich et al., 2015; Institute for Patient- and Family-Centered Care, 2018; Kuo et al., 2012). CFCC builds on the idea of family-centered care and is argued to extend the latter in important ways that take into account children’s agency (Coyne et al., 2016; Einboden et al., 2013b) and human rights to participate in health care decisions that affect them (Coyne et al., 2016; Ford, 2017; Grahn et al., 2016). However, the extent to which CFCC can address shortcomings of family-centered care has not been established. According to the extant literature, CFCC has yet to be explored in the context of families and children whose health and health care is likely to be compromised by multifaceted social and structural factors, including racialization, material deprivation, and historically entrenched power imbalances. This is a critical area of inquiry, given the increasing evidence that children in families who face such inequities have poor health outcomes (Bell et al., 2013; Boyce and Hertzman, 2018; Carter, 2018; Durkin and Yeargin-Allsopp, 2018; Liming and Grube, 2018; Shonkoff, 2012). Despite the lack of consensus regarding what constitutes CFCC, and to date, the inattention to the relationship of CFCC to social and economic inequities, we contend that this approach has considerable potential for promoting health and health care inequities. The emphasis on agency and participation of both children and their caregivers provides important grounding essential to an equity orientation.

This article examines dominant discourses of CFCC in the context of families and children who are at greater risk of health inequities in wealthy countries, drawing on Canada as a useful example. As a country structured by race-based colonialism, the economic and social positions of families and children who are Indigenous, or who have come to Canada as immigrants or refugees and are racialized within the white-dominated society are instructive to many colonial countries where inequities are widening along these dimensions. This article also outlines an evidence-based approach to equity-oriented care that the authors contend has the potential to orient CFCC toward equity and provide greater clarity in the conceptualization, implementation, measurement, and evaluation of CFCC in ways that can benefit all families and children including those who have typically been excluded from research.

**Childhood adversity and health inequities**

The former Chair of the World Health Organization’s (WHO) Commission on Social Determinants of Health, Sir Michael Marmot (2011) has called for “equity for every child from the start” as a fundamental aspect of addressing health inequities within and between countries (p. 702). The WHO defines health equity (World Health Organization, 2008) as the absence of systematic and remediable differences in one or more characteristics of health across socially, economically, or demographically defined populations or population groups. Health inequities are closely connected to the distribution of power and wealth within a society and the social conditions in which people live (World Health Organization, 2008). Health inequities are thus “unfair, avoidable, and remediable differences in health status between countries and between different groups of people within the same country” (World Health Organization, 2013).
Children’s experiences of health and health care inequities are structurally rooted in and continuous with the impacts of intersecting social determinants on their family’s everyday lives and well-being (Gerlach et al., 2018). From this perspective, addressing child health and health care inequities is inseparable from engaging with and supporting the well-being of the family as a whole; recognizing the diversity of what can constitute “family” in contemporary societies. Addressing children’s experiences of health and social inequities, particularly from the prenatal period to age five, is of critical concern because they can result in an increased risk of poor health outcomes and adverse life experiences across their life course (Bell et al., 2013; Boyce and Hertzman, 2018).

Globally, in diverse contexts, there is increasing evidence that health and health care inequities are significantly and positively correlated with experiences of racialization, socioeconomic inequities, and systemic and interpersonal discrimination (Allan and Smylie, 2015; Bastos et al., 2018; Fitzsimons et al., 2017; Marmot, 2013; Philbin et al., 2018; Wilson et al., 2017). In Canada, child populations that are particularly vulnerable to health inequities include children in lone parent families led by women (Gurstein and Vilches, 2011); children in “state care” (Representative for Children and Youth, 2014); Indigenous children (Blackstock, 2016; Smylie et al., 2010; Stewart et al., 2013); and children in families who experience racialization, stigma, and/or social marginalization (Dunn and Dyck, 2000; Representative for Children and Youth and Office of the Provincial Health Officer, 2015). In the Canadian context, a stark example of health inequities is evident in the country’s differing rates of infant mortality in the first year of life, which is recognized worldwide as a fundamental indicator of the well-being of a society. The average infant mortality rate in Canada is estimated to be 4.4 infant deaths/1000 in their first year of life. For families living in Inuit Nunangat, the homeland of the Inuit in Canada, the rate is estimated to be 12.2 infant deaths/1000 live births (Inuit Tapiriit Kanatami, 2018). This higher rate is largely due to potential remediable structural inequities, rooted in historical and ongoing colonialism, that result in many Inuit families lacking basic determinants of health including housing and food security for their children in their first year of life (Inuit Tapiriit Kanatami, 2014).

Participation as a key element of child- and family-centered care

In recent years, a philosophical shift from “family-centered care” to CFCC aligns with a growing recognition of children as social agents (Coyne et al., 2016; Einboden et al., 2013a; Einboden et al., 2013b) and international calls to uphold children’s rights to participate in health care decisions that affect them (Ehrich et al., 2015; Ford, 2017; Grahn et al., 2016). Key elements of CFCC include health care providers: (1) listening to and honoring families and children’s perspectives and choices such that their knowledge, priorities, concerns, and beliefs are incorporated into the planning and
delivery of care; (2) providing families and children with timely and accessible information in ways that are affirming and foster their participation in care and decision-making; and (3) supporting families and children’s participation in care and decision-making at a level of their choosing (Byczkowski et al., 2015; Conway et al., 2006; Dennis et al., 2017; Ehrich et al., 2015; Institute for Patient- and Family-Centered Care, 2018; Kuo et al., 2012).

Health systems and policies that support children’s participation are increasingly viewed as essential for optimizing children’s health and health care outcomes (Davies and Randall, 2015; Ehrich et al., 2015; Moore and Kirk, 2010), improving families’ experiences of care and staff satisfaction, and a wiser allocation of resources (Institute for Patient- and Family-Centered Care, 2018). Evidence points to some children preferring to be included in interactions and decisions about their care, with physical and psychological benefits as children gain more knowledge about their health condition and a greater sense of self-determination (Coyne et al., 2016; Jones et al., 2012). Children who participate in their own care may also experience less pain and discomfort than children who are not involved (Grahn et al., 2016). Involving family members in providing essential physical, social, and emotional support in pediatric emergency care is also associated with improvements in children’s recovery and health outcomes (Brysiewicz, 2017).

Evidence indicates, however, that while CFCC is evident within the rhetoric and motives of pediatric care policies, its implementation is highly variable (Coyne, 2008; Dennis et al., 2017; Ehrich et al., 2015; Hemingway and Redsell, 2011; Jeremic et al., 2016; Kuo et al., 2012; Moore and Kirk, 2010). Child and parent participation is a complex endeavor influenced by multiple and intersecting factors including whether and how health care providers include children and parents in decision-making (Aarthun et al., 2018) and how relational processes of care are shaped by inherent clinician–patient power imbalances (Berry et al., 2017; Shields et al., 2012). For children, their agency and participation can also be shaped by the adults present, both parents and health care providers, who may have differing opinions about children’s care-related decisional capacity and the preferred extent of their involvement (Davies and Randall, 2015; Jeremic et al., 2016; Rasmussen et al., 2017). Factors that constrain physicians’ facilitation of children’s participation can include lack of time, loss of power and control, and uncertainty about children’s competence related to their age (Coyne, 2008; Ehrich et al., 2015).

CFCC discourses tend to reflect and reproduce Euro-western values and assumptions about participation, predominately from the perspectives of middle class health care professionals located in predominately urban settings (Alabdulaziza et al., 2017; Foster and Whitehead, 2017; Jeremic et al., 2016; Jessup et al., 2017; Smith et al., 2017). The relevancy, ethics, and efficacy of implementing CFCC in diverse sociocultural, economic, and geographical contexts have yet to be adequately explored. Moreover, there is a paucity of critical analysis on how CFCC is, or could be, inclusive of and responsive to the priorities and preference of parents and children with diverse social identities, locations, and circumstances (Shields et al., 2012; Wood and Goldhagen, 2013) that can profoundly shape access to equitable health and health care. Critical engagement with CFCC is therefore required in order to resist essentialized views of CFCC being applied universally and failing to address child health and health care inequities (Wilson et al., 2017), and to resist CFCC being seen as a panacea for the limitations of family-centered care.

**Orienting child- and family-centered care toward equity**

The field of research into health equity is well established (Rasanathan and Diaz, 2016). However, evidence about how health care systems can contribute toward preventing and mitigating child
health inequities is in its infancy in Canada (Gerlach et al., 2018; Lynam et al., 2011) and internationally (Goldhagen et al., 2015; Morrison et al., 2017; Marmot, 2011; Schleiff et al., 2017). In Canada, some pediatric institutions claim that CFCC is central to achieving health equity (Sick Kids, 2014). However, there is limited knowledge on how parents’ social identities shape their children participation in care (Coyne, 2008) and a paucity of research on CFCC that is inclusive of the perspectives of families who are at greater risk of health and health care inequities. As discussed, CFCC is a participatory, dynamic, and relational process. However, what participation looks like has not been adequately explored. Moreover, participation has not been explored at all from the perspectives of families who may be reluctant to access health care for their children for a variety of reasons, including parental concerns related to social marginalization, anticipated stigma and discrimination, and previous negative interactions within health care settings. Thus, while CFCC has been promoted as essential and linked to fostering equity, an equity orientation has not been examined or developed. Indeed, according to the extant literature, CFCC has yet to be explored with families and children who are vulnerable to health inequities as a result of multi-faceted personal, social, and structural factors. Consequently, there is a need to expand the conceptualization and application of CFCC toward equity.

The aim of CFCC is to reframe the relationships in pediatric health care in recognition of families and children being ‘essential allies’ in direct care interactions, quality improvement initiatives, organizational design, and policy development (Curran et al., 2018; Institute for Patient- and Family-Centered Care, 2018). Relational approaches that support child and family participation in decision-making and care are central to CFCC and well aligned with the prevailing ideology of patient involvement in health care reform in Canada and internationally (Laurance et al., 2014; Manafo et al., 2018). Relational approaches are built on an understanding of how people mutually influence one another and their environments and require taking the contexts of people’s lives and health care into account in health care practice (Doane and Varcoe, 2015; Hartrick Doane, 2015; Varcoe and Doane, 2015).

Relational approaches and participation in decision-making and care have been shown as central to equity-oriented care with primarily adult populations (Browne et al., 2018). EQUIP Health Care (https://equiphealthcare.ca/) is an evidence-informed approach codeveloped by Varcoe and colleagues (Browne et al., 2012, 2016). EQUIP research is the first to empirically show that people living in marginalizing conditions who receive equity-oriented care experience improved health outcomes over time; the extent to which they experience care as equity-oriented, predicts a higher level of confidence and comfort with the care they receive, which in turn predicts their own comfort and confidence in managing and preventing their own health problems, which is associated with better quality of life, lower depressive symptoms, fewer trauma symptoms, and less disabling chronic pain (Ford-Gilboe et al., 2018).

EQUIP is centered on three key dimensions: cultural safety, trauma- and violence-informed care (TVIC), and harm reduction, all of which must be tailored to the context (Browne et al., 2015, 2016, 2018; Ford-Gilboe et al., 2018; Wong et al., 2014). **Cultural safety** focuses on addressing structural conditions to support changes to dominant norms to enhance care for everyone, not just those presumed to be “different” (Browne et al., 2015; Gerlach, 2012; Varcoe and Browne, 2015). **TVIC** is an approach to policy and practice interventions developed by Varcoe and colleagues to minimize harm and promote healing by understanding experiences of past and ongoing interpersonal and structural violence as causes of trauma and taking action at health care practice and organizational levels and as a society (Ponic et al., 2016; Varcoe et al., 2016). **Harm reduction** involves practices
that mitigate harms of substance use and harms associated with the historical, sociocultural, and political determinants of drug use and drug and health policy (Smye et al., 2011).

These three key dimensions have yet to be explored in research examining CFCC. It has been proposed that cultural safety and TVIC are central to providing Indigenous mothers in Canada with equitable access to family-centered primary health care for their infants (Wright et al., 2019). Also, research in the Canadian context led by the primary author indicates the relevancy of the dimensions of EQUIP for Indigenous families and children whose equitable access to health and health care are compromised as a result of intersecting social and structural factors [references removed for anonymity].

Each of the key dimensions of equity-oriented care described above has patient participation as a central tenet (Gerlach et al., 2018, 2017a; Ponice et al., 2016; Smye et al., 2011; Varcoe and Browne, 2015). This, taken together with the shifts heralded by the move from family-centered to CFCC, indicates a foundational understanding is required regarding what would be needed to address each of these key dimensions in pediatric health care. Importantly, the key dimensions can not only orient CFCC toward equity but also provide greater conceptual clarity related to discussions on what constitutes CFCC and direction on how to implement, measure, and evaluate CFCC. For example, informing CFCC from a cultural safety perspective has the potential to promote efforts to reduce and mitigate the impact of systemic and interpersonal racism and provides a basis for developing trusting relationships when racism is an ongoing threat to well-being. Moreover, a recent dissertation focused on cultural safety in the context of child health in Aotearoa/New Zealand suggests that Maori and Pacific whanau approaches could prompt a fundamental restructuring of health care for families and children (Brown, 2018). Similarly, employing a lens of TVIC to how CFCC is conceptualized and enacted can inform relational practices that have the potential to mitigate multigenerational impacts of historical and ongoing interpersonal violence that often affect the well-being of those experiencing structural inequities and provide a foundation for relationships based on understandings of families’ life circumstances, histories, and traumatic experiences. Finally, applying a harm reduction philosophy and approach to CFCC, not only to parents with problematic substance use but also as a lens on prevention of such problems, can help attenuate the harms of stereotyping related to substance use that families encounter, with impacts on their access and quality of health care. Importantly, this approach can help mitigate children’s health care inequities as a result of their parents’ reluctance to access care for fear of stigma, stereotyping, or state child apprehension.

Taken together the key dimensions of equity-oriented care based on EQUIP research have the potential to inform how CFCC can be tailored in response to the social contexts and complexities of families and children’s lives and inform relational practices that mitigate power imbalances in patient–provider relationships and promote the development of trusting relationships. Such relational approaches are supported by evidence that trusting patient–health care provider relationships can result in increased patient participation in care (Murray and McCrone, 2015). Orienting CFCC toward equity based on the key dimensions outlined above also provides greater clarity for measuring and evaluating its impact in ways that can benefit all families and children including those who have typically been excluded from research.

**Conclusion**

The provision of CFCC is a complex process that continues to lack empirical evidence, conceptual clarity, and consensus regarding its implementation. As highlighted in this article, there is also a scarcity of evidence in Canada and internationally on how health care services that claim to be
child- and family-centered are/can be responsive to families and children who experience a greater risk of health and health care inequities. This article outlines a potential evidence-based approach to orient CFCC toward equity that has the potential to clarify its conceptualization, implementation, measurement, and evaluation. Given the growing recognition for socially responsive and inclusive health care approaches that mitigates the impacts of childhood adversity across the life course, this article suggests that there is an immediate need for research on how CFCC can be inclusive of and responsive to families and children who are vulnerable to health and health care inequities. There is also a need for further research that recognizes children’s agency and methodologies that are inclusive of children as coresearchers and participants.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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Notes

1. Some conceptualizations of “family-centered care” include the role and participation of children. For the purposes of this article and consistent with exploring issues of equity and children as social agents, the term child- and family-centered care is used.

2. “Participation” has been conceptualized and used differentially in numerous studies (Murray and McCrone, 2015). For the purposes of this article, the term participation is used broadly as a way of describing parents and children’s contributions within health care consultations or discussions about them; acknowledging that the extent to which a child can participate will vary depending on multiple factors including their age and health care needs.

References


